

STATE OF CONNECTICUT

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Testimony of the Office of Protection and Advocacy for Persons with Disabilities Before the Public Health Committee

Presented by James D. McGaughey
Executive Director
March 12, 2008

Good morning and thank you for this opportunity to comment on several of the bills on your agenda today. They are:

Raised Bill No. 5666, AN ACT CONCERNING EXPANSION OF THE PILOT PROGRAM FOR PERSONS WITH AUTISM SPECTRUM DISORDERS. As the title suggests, this bill calls for the limited expansion of a pilot program operated by the Department of Developmental Services for people who have autism spectrum disorders. That program, which was the result of many years of study, planning and advocacy, is already proving to be quite useful to those lucky enough to live within the geographic area it serves. Our Office is aware of people who could benefit from the program, but who just happen not to be living in the right place. Although it is still considered a "pilot" program — meaning that there are still things we want to learn from the experience of operating it on a small scale before making decisions about long term commitments — we already know so much about the needs of people on the autism spectrum, and DDS has gone through enough of the "start-up" process to confidently say that expanding the scope of the program is fully warranted. So, I urge you to support this direction.

Raised Bill No. 5541, AN ACT CONCERNING SEXUAL ASSAULT OF PERSONS PLACED OR TREATED UNDER THE DIRECTION OF THE COMMISSIONER OF DEVELOPMENTAL DISABILITIES. This measure would allow a charge of second degree sexual assault to be brought against someone who has supervisory or disciplinary authority over a person placed or treated under the direction of the Commissioner of Developmental Disabilities and who has sexual intercourse with that person. Current statutes only allow this charge to be brought when the victim is in a hospital or institution. Because the vast majority of DSS clients are no longer served in institutions, but rather are placed or treated in community-based programs, prosecutors have been reluctant to charge caregivers who engage in sexual misconduct with their clients.

Our Office supports this measure. I only wish its provisions could reach to people with developmental disabilities who are not placed or treated under the direction of the Commissioner. There are a number of people with intellectual disabilities who receive no DDS services, or only very minimal services such as case management or occasional respite. Some of these people live with their families, others on their own. In the course of investigating allegations of abuse and neglect, our Office periodically encounters individuals who have intellectual disabilities, but who are not DDS clients and who are being sexually exploited by persons with apparent authority over them – a former foster parent, a van driver, a stepparent. If

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we substantiate abuse or neglect, we can make a recommendation for protective services to DDS. But criminal prosecution does not usually occur. Optimally, we could find a way to secure justice for these people too.

Raised Bill No. 5861, AN ACT CONCERNING MENTALLY ILL INDIVIDUALS IN NURSING HOMES. This bill calls for the Department of Mental Health and Addiction Services (DMHAS) to establish "minimal reasonable standards" for the care and treatment of people with mental illness who reside in nursing homes. Facilities that admit individuals with mental illness would then be required to report annually to the Department of Public Health that they satisfy those requirements. While the bill recognizes that the situation of people with psychiatric disabilities in nursing homes needs to be addressed, I am concerned that it does not go far enough, and that it may even contribute to an illusion that nursing homes can be made into satisfactory places to house people with serious mental illness.

Several years ago the Lt. Governor's Mental Health Cabinet reported that close to 2,700 individuals with serious mental illness were residing in Connecticut nursing homes, and that the number was increasing by between 5-10% per year. Nearly half of these people are younger than 65 years of age. They are not people who are dangerous to themselves or others; most could live successfully (and much more cheaply) in homes in their communities with varying levels of support. Yet they are being segregated, isolated, regimented, are loosing relationships and independent living skills, and are being deprived of their liberty, - often literally locked up and not allowed to leave their units. In many ways, nursing homes (and prisons) have become the functional equivalent of the back wards of the old state mental hospitals.

Having a mental illness - even a significant and persistent one - need not be life defining. We know a lot about what people need to live productive, contributing, participating lives, and we know a lot about how to help. You don't do that by institutionalizing people. The more you institutionalize people the more you create career mental patients; it's a waste of people's lives, as well as a waste of precious public resources.

The real solution to this costly problem lies not in establishing minimal standards of care and treatment in the facilities, but in recognizing that most of these people do not belong in nursing homes in the first place, and then investing in the types of supportive housing and community-based support services that we know can work.

Having said that, however, I acknowledge that some people with serious mental illness are admitted to nursing homes because of a physical illness or condition that requires a high level of nursing care. Those individuals should receive appropriate care, including psychiatric treatment and appropriate programs. However, I believe that assuring that such needs are met would require more than minimal standards and an annual affirmation by facilities that they are meeting those standards. I am aware that other advocacy groups testifying today are suggesting language that would require DPH to review the plans and care of a representative sample of residents with

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psychiatric disabilities in their annual surveys. That approach would probably prove more effective than asking facilities to self-report. But, again, I do not think we should delude ourselves into thinking we can transform nursing homes into the real homes and community support service that the majority of people with serious mental illnesses who are currently housed in nursing homes need in order to realize the promise of recovering their lives.

Raised Bill No. 5810, AN ACT CONCERNING THE PROVISION OF BEHAVIORAL HEALTH SERVICES IN EMERGENCY ROOMS. This bill would require DMHAS and DSS to establish cooperative pilot programs geared toward helping people with psychiatric disabilities who present at hospital emergency departments, to move directly to more appropriate sources of assistance. The regional programs it envisions resemble the successful Alternatives to Hospitalization (ATH) pilots that DMHAS has already begun to operate in urban hospitals for recipients of State Administered General Assistance. Given the length of time many people must wait in emergency departments to be seen and appropriately referred, admitted or discharged, and the widespread gridlock gripping emergency departments across the State, expanding the ATH approach to a broader group in different geographic areas makes a lot of sense. I would point out, however, that underlying the problem of emergency room gridlock is a general problem with the availability of behavioral health services. Figuring ways to expedite referrals will only go so far. We also have to invest in longer term solutions like expanding the availability of supportive housing and relevant, recovery oriented services.

Thank you for your attention. If there are any questions, I will try to answer them.